



# COPING WITH A DIAGNOSIS OF MDS

MDS UK SUPPORT GROUP

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# EVERYONE'S DIFFERENT...AND AT DIFFERENT PLACES

- Coping with MDS has a lot to do with whether you're on treatment, on 'active monitoring' only, transfusion dependent/ independent, approaching intensive treatment or post-treatment (for eg stem cell transplant)

# DISTRESS IS NORMAL

Even if you have had the diagnosis for a while – distress can peak and trough at key points (if something changes, or before blood tests or bone marrow biopsies)

Can be low mood about the present or anxiety about the future

Natural process of adjustment includes initial period of shock/ distress followed by an acceptance of new routines/ normality.

Giving yourself time if you're newly diagnosed or if something has recently changed in your condition is vital

For those on 'Active monitoring' – burden of 'knowledge' - particular concerns around 'feeling like everything has changed' when practically things are the same as before

# MYTHS AND FALSE EXPECTATIONS OF EMOTIONAL WELLBEING

- That I should 'just be grateful' or 'happy' if I'm currently well
- That I need to be positive or strong all the time
- That I should simply be able to move forward in my life with my goals or aspirations
- That I'm being 'negative' by worrying about things getting worse
- That such fears are abnormal or irrational because 'there is no reason to feel like this'
- That I need to get rid of this fear in order to live my life
- That what's the point in having these feelings since I can't change the situation anyway

Revising our expectations, recognising these as 'myths' can help us accept our emotions and thoughts

# SELF COMPASSION

When you're feeling unsettled/ distressed/ upset, ask yourself.....

‘What would I say to someone I love if they were feeling this way or having these thoughts?’

Helps us access a compassionate voice

Actively say the same thing to yourself in a gentle and loving tone

Sounds awkward... and it can feel awkward but practicing this over time helps us tolerate our thoughts and emotions

# HELPFUL WAYS OF COPING WITH UNCERTAINTY

## Understanding why we dislike uncertainty and have anxious thoughts

Two basic human needs: To prevent dangers and to avoid unpleasant emotional states (eg. Regret)

'Problem solving machine' → priority is our survival so it scans for threats and risks

Your mind doesn't want you to go through what you went through again (shock, disappointment)

This is what gives rise to thoughts/ worries about relapse or future threats

## ALL OF THIS IS NORMAL

What human beings crave (predictability, certainty) and what life offers (unpredictability, uncertainty) often don't match

A serious illness (understandably) heightens the sense of danger and uncertainty

# HELPFUL WAYS OF COPING WITH UNCERTAINTY

## **Balance between planning and taking ‘calculated risks’/ hoping for the best**

People vary in how much they want to know about the disease → get the information you need/ want

Confront rather than avoid anxious ‘what if’ thoughts → connects us with problem solving part of the mind

Our minds can time travel, but we can only influence events in the present.

Try asking yourself ‘what can I do about it now? Tomorrow? Next week?’

- If you can do something, do it.
- If you can’t, remind yourself with kindness that ‘we have to wait and see’

Accept what you can’t change (predicting the future) and work within those limits

Best we can do is make realistic plans (that feel achievable when you make them) and hope for the best (PS- you were already doing this before)

# HELPFUL WAYS OF COPING WITH UNCERTAINTY

## Uncertainty about side effects –How long will they last?

- Keep medical guidance in mind
- Remember you can cope with things as they arise and your team are there to help
- Try to reframe negative conclusions (“I will never get better”) to slightly more balanced one (“I don’t know when I’ll feel better; what is happening isn’t my fault; I can only do what is needed/ do my best”)
  - ~ This gives us space to try to make the most of now ~

# HELPFUL WAYS OF COPING WITH UNCERTAINTY

## **Believe in your capacity to adapt**

Accepting the unpredictability of life involves learning from experience

Remember....

We always underestimate our ability to cope with a future threat

We are all more resilient than we think we are

# HELPFUL WAYS OF COPING WITH UNCERTAINTY

**Learning to observe our thoughts – take a step back from our thoughts – reframe our thoughts**

We can get swept up in our thoughts and worries

Learning to put some distance between us and our thoughts can help

“I might get sicker” -----→ “***I’m having the thought that*** I might get sicker”

Mindfulness techniques help us develop this skill of observing our mind without getting caught up in it (apps like Headspace, Calm)

## SOFTENING OUR BELIEFS...

### Rigid beliefs that increase sense of threat

'I need to know in order to cope'

'I need to plan'

'I need to be in control for things to be okay'

'I have to make the right decisions'

### Gentler beliefs that can reduce sense of threat

Not knowing is uncomfortable but I can try to work with what I know so far

I'll try to plan as much as possible, and deal with the rest as it happens

I can figure things out. I can be okay even if some things are not in my control

There is no perfect answer. I can only do my best and make a decision based on the information I have right now

# HELPFUL WAYS OF COPING WITH UNCERTAINTY

## **Practice attentional control**

### **Re-focus on the ‘here and now’ if preoccupied by questions about future possibilities**

- Refocus to the here and now using words ‘I’m having all these thoughts about the future, but right at this moment, nothing has changed’
- Breathing exercises to help bring attention / awareness to the present moment + relax the body and mind in overwhelming moments
- Practice

# HELPFUL WAYS OF COPING WITH UNCERTAINTY

## **Find the small certainties within larger uncertainties**

Remind yourself what IS in your hands

When your mind dwells on ‘What is going to happen?’ instead try to ask yourself

- What do I know now?
- What do I have now?
- How can I honour and invest in this?

Small goals, aspirations, plans

Maintaining some routine/ predictability can help

## WHERE TO GET HELP

- Local NHS Talking therapies services
- Charities/ voluntary organisations providing low cost/ free counselling
- Cancer charities like Macmillan or Maggie's – Macmillan provides up to six sessions of counselling via BUPA
- Not everyone needs to see a psychologist or psychotherapist
- Existing resources that have helped you through tough times before
- Peer support



THANK YOU FOR LISTENING

Questions?